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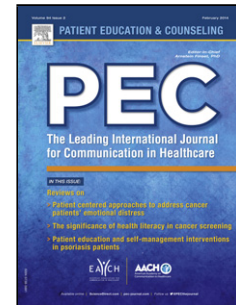
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Accepted Manuscript

Title: An e-health intervention to support the transition of young people with long-term illnesses to adult healthcare services: Design and early use

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Title: An e-health intervention to support the transition of young people with long-term illnesses to adult healthcare services: design and early use.

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Highlights

- Successful transition to adult healthcare requires information and preparation.
- Adolescents receive limited information about transition.
- Digital technologies may help engage adolescents in their healthcare.
- Innovative online resource developed through a participatory iterative process.
- www.SteppingUP.ie. provides information and guidance for transition.

Abstract

Objective: Co-design information and website to support adolescents and young adults with long-term illnesses in their transition to adult healthcare.

Methods: A participatory iterative process involving a survey (n= 207), twenty-one interviews, six participatory workshops, six video recordings, two advisory groups, and a co-design group to identify needs and preferences for e-health and information provision, was used to develop an appropriate intervention.

Results: Adolescents and young people expressed preferences for information that was trustworthy, empowering, colorful, easily downloaded online and written using non-patronizing language. They desired video testimonials of experiences from young adults who had transitioned to adult healthcare and wanted advice about becoming more independent, managing their condition, preparing for the transition, and information about medications and the differences between child and adult healthcare. They also wanted information about the location and configuration of adult healthcare, key hospital personnel, and frequently asked questions.

Conclusion: The participatory iterative process led to the development of an online resource specifically tailored to the adolescents and young people's transition needs and information preferences. Preliminary feedback indicates that it is a valued resource.

Practice Implications: The www.SteppingUP.ie website has the potential to help prepare its target population group for the transition to adult healthcare.

Keywords: Transition; information; self-management; patient-centered communication; engagement; adolescents; young adults

1. Introduction

Health information communication technology (HICT) has the potential to promote self-care in the management of chronic conditions as it appears to improve communication through the efficient delivery and synthesis of information [1, 2]. Improvements in knowledge [3], problem-solving and self-management [4, 5] and HbA1c levels [6] have been reported for young people with diabetes using HICT. Adolescents and young adults (AYAs) are frequent users of the Internet, and are commonly seen as the 'digital native generation' due to their familiarity and ease with digital technology from an early age. Consequently digital technologies are increasingly being used to share information and engage AYAs in their healthcare [7, 8]. Finding ways to promote and empower AYAs' participation in self-care is essential as it enhances chronic illness management and contributes to a successful transition from children's healthcare to adult healthcare [9]. This paper describes the development of a web-based health information intervention to support and prepare AYAs with chronic conditions for transition to adult healthcare.

Medical advances are enabling more than 85% of children born today with chronic conditions to reach adulthood with many transferring to adult healthcare [10]. In Ireland and worldwide, the numbers of young adults with congenital heart disease (CHD) [11], cystic fibrosis (CF) [12], and Type 1 diabetes (T1D) [13] are increasing rapidly. A successful transition is defined as a: "purposeful, planned process that addresses the medical, psychosocial, educational and vocational needs of adolescents and young adults as they grow up learning to live with their lifelong health condition" [14]. This shifts the focus of transition from the negotiation of structural boundaries between services to the developmental needs of adolescents and young adults. A well planned transition appears to lead to improved adherence to appointments [15, 16], improved patient satisfaction [17-19] and parent satisfaction [19], stable or improved disease control [20], improved relationships with health care professionals (HCPs) [21, 22] and promotion of autonomy [21]. Inappropriate or inadequate transition is associated with poor clinic attendance [23], loss to follow-up, increased non-adherence to treatment, increased morbidities, increased emergency/hospital admissions [24] and adverse health outcomes [25-27]. Therefore effective transitional care can prevent deterioration in young people's health and their disengagement with healthcare [28, 29].

Research indicates that many AYAs feel unprepared, lack knowledge about transition and development of self-management skills and receive limited information about adult services [9, 30, 31]. A review of AYAs with CHD transition experiences concluded that AYAs needed education on the implications of their condition, the differences between pediatric and adult healthcare, and self-care management [32]. A review AYAs with T1D transition experiences found that AYAs needed to develop independent self-management and self-advocacy skills to navigate the transition and adult

healthcare, but some were inadequately prepared for this [23]. Clearly young people require better support and preparation to make a successful transition from child to adult healthcare. We wanted to find an innovative way of information provision beyond traditional formats (leaflets). The intention was to co-create an e-health intervention which would be user-led and user-friendly and yielded a co-designed website and information resource called www.SteppingUP.ie to address information and preparation needs prior to transition.

2. Methods

The aim was to co-develop an e-health information intervention to support young people with long-term illnesses transitioning to adult healthcare.

The objectives were:

1. To co-design materials and a website with AYAs to reflect their knowledge needs for transition.
2. To ensure that AYAs with long-term illnesses were involved in every stage from inception to the final product.
3. Enable the personalization of the content so that AYAs can save, share, view offline or download as an application.
4. Include interactivity to help memory recall of key information about transition.
5. Optimise the website so that it can be downloaded as an application for smartphones and tablets.

2.1 Research design

The study used a participatory approach viewing AYAs' input as a central element in the design and development of the website and its content. The participatory approach involves co-learning and reciprocal transfer of expertise, shared decision-making and mutual ownership of process and products of the enterprise [33]. It was underpinned by four key principles: consultation and cooperation with relevant stakeholders; experimentation with alternative designs; contextualisation (testing with users and providers); and iterative development (modification in response to evaluation) [34]. The study comprised four phases (see Table 1).

Insert Table A.1 here

2.2. Sample

This study builds upon the findings of a transition project (called TRYCIS) which investigated the transition experiences of AYAs (with CHD, CF, T1D), parents and healthcare professionals [35]. Data on information needs and preferences for e-health technologies were obtained through a postal survey

(n=207) and interviews (n=21) with AYAs aged 14 to 25 years old with T1D, CF or CHD. **The e-health survey statements and interview questions are outlined in Table 2.**

Insert Table A.2 here

The sample for the development of the website was recruited via email invitations to those who had taken part in the TRYCIS project, promotion through voluntary organisations for each of the three conditions and calls 'of interest' on social media. The final sample comprised: the co-design group of experienced AYA consumers of healthcare aged 15-25 years (n=5), telephone interviews (n=4) and participatory workshops (n=12). The AYAs received a €20 gift voucher as a token of appreciation for their participation.

2.3. Ethical considerations

Ethical approval for the study was obtained from the Faculty Research Ethics Committee, Trinity College Dublin. Informed consent was gained from all participants and parents where adolescents were under 18 years.

3 Results

3.1. Phase 1- Consultation and cooperation with relevant stakeholders

Identify information needs and preferences

The TRYCIS survey data revealed that almost 6 in 10 young people (57.1%) believed that a website would be quite or very useful for receiving information about their illness. Mobile phones/apps were deemed most useful (76.9%) while technologies such as Skype (15.7%), social networks (50.8%) and chat rooms (25.2%) were viewed as not very useful. Email (34.5%) and web pages (33%) were the preferred options for the exchange of information about their disease and for receiving advice/support and information on healthcare facilities (see Table 3).

Insert Table A.3 here

The TRYCIS interview data revealed that the transition was very difficult for some AYAs, and that they wanted advice, information, support and signposting about transition but they encountered obstacles to having these needs met. Some experienced an abrupt move from child to adult healthcare and did not receive adequate preparation and information. The AYAs reported that they would be happy to use the telephone and email for communication and a trusted website for information on transition. Many felt that a website that was designated specifically for the transition to adult healthcare would be very useful. They identified a number of needs and preferences which included: information about the new adult clinic, what to

expect at the adult clinic and other young people's experiences of transition. They stated that the website would need to be 'recommended' and they would need to 'trust' the information on the site. Overall, the AYAs suggested that the website would be useful as they could 'browse in their own time'. One young person said that they were 'totally visual' and did not like to 'sit down and read' so that they would like the idea of a website with easily accessible information (see Table 4).

Insert Table A.4 here

Establish co-design and advisory groups

Using a participatory approach, a co-design group was established comprising five AYAs aged 15-25 years from the three disease groups. The group included three females, two of whom had already made the transition, and two male participants, one of whom had made the transition. These AYAs played a key role in reviewing the website materials and developing the site **layout and content. They were the main opinion leaders on all aspects of the project and had the final say on the content and presentation of website.**

An advisory group (doctor, nurse, parent, young adult, clinical psychologist, lecturer, web developer, digital technology expert) **helped steer the project.** A second advisory group (parents and members of Cystic Fibrosis, Diabetes and Heart Children, Children in Hospital, Ireland) **provided expertise from disease groups involved in information provision. Including these stakeholders was viewed as contributing to support for and promotion of the intervention.**

3.2. Phase 2: Experimentation

Using the data on AYAs' information needs and preferences (from Phase 1), the research team collaborated closely with the AYAs to co-design and co-develop the website and its material. The process of developing and refining the information on transition requirements and designing the website involved conducting participatory workshops, one-to-one interviews and video recordings of transition experiences. In addition, adult health clinics were contacted and asked to provide photographs and completed standardised forms providing details identified by AYAs as useful, e.g. clinic times and procedures, personnel, maps, facilities. Two participatory workshops were conducted with AYAs (n=12) **and telephone interviews with AYAs (n=4) with CF** aged 15-25 years (who had received materials prior to the interview). **Both workshops and interviews were recorded and transcribed verbatim and observational notes were taken. Data were analysed using simple content analysis. The analysis was guided by the**

three identified stages of transition - thinking about transition, planning your transition and making the transition.

In the workshops and during the interviews, the AYAs were asked to share their advice and key steps in making the transition to adult healthcare and also to make a list of any questions that they would like (or have liked) to ask about transition. They were asked to discuss key concerns and expectations about transition. In addition, they were shown 'mock ups' of a possible site layout and some materials for the site and asked to review the format, content and appropriateness of these. Gaps in information were noted by the research team with areas for further exploration agreed with the AYAs. Both groups comprised a mix of AYAs who had not yet made the transition and those who were in the process or had transitioned up to a year previously. This worked well as the older participants were able to provide useful information which prompted the younger participants to ask more questions and voice their concerns. With permission, the workshops were digitally recorded, and transcribed so that the valuable input from the AYAs could be fully captured and used in the development of website content and materials. Worksheets used during the workshops were also used to ensure all 'tips' and 'questions' were taken into account on the the final website development.

The AYAs indicated that a website should be user-friendly and trustworthy and provide practical information on what to expect when making the transition. The website should provide information on differences between child and adult healthcare; the clinics, location and configuration of services, opening times, key staff members; FAQs, illness management 'tips' and transition experiences of other AYAs with chronic conditions. More importantly, they indicated that they would like to see testimonials (patient experiences) from other young adults who had experienced a transition to adult healthcare. The development of the information resources and website was an iterative process as the team (researchers, AYAs, web designer) experimented with different designs through several participatory workshops. The website developmental materials underwent numerous revisions until a consensus was reached.

4.2 Phase 3: Contextualisation and iterative development

The name for the website was a key decision at this stage, as the name would communicate the vision and purpose of the site. A short SurveyMonkey questionnaire was developed and sent to all those involved in the participatory workshops and interviews, the TRYCIS project participants (young people, parents, healthcare professionals) and voluntary organisations on the advisory group to maximize participation in the decision. Participants (n=74) were given 10 possible names (derived from workshops/ interviews/ meetings) and asked to choose their 'top 3'. 'SteppingUP' was chosen by the majority of stakeholders.

Using an iterative process, the website design and materials were tested and modified in response to evaluations by AYAs primarily, and latterly by all other stakeholders. For example, the wording needed to convey information as empowering rather than being patronizing or adult orientated. The demonstration website was then usability tested with AYAs in the co-design group and by healthy AYAs to determine how well the site functioned and ease of navigation. The AYAs were encouraged to verbalise aloud and the researchers recorded the participants' reactions and comments about the site. The feedback indicated that, while the layout was good and navigation easy, some elements of the design would need modification. The participants' felt that the pages were too long and contained too much information; the colour (in the orange range) was not liked, a light blue or yellow was preferred; the picture of the 'young person' on each page was "annoying" and a bit "cheesy"; and someone did not understand what "FAQ" stood for. The demonstration website was also tested with members of the two advisory groups. Testing of the content (information material) and web design by the co-design group and advisory groups led to further changes and modifications.

On further testing of a revised demonstration website, the co-design group viewed a video of one of the finished 'transition stories' and the feedback was very positive. They agreed that the length (2-4 minutes) was 'perfect', long enough to provide adequate information and short enough to hold a young person's attention. Other issues that were highlighted included the need for the information to be phrased in simple English, but not 'babyish', and to use terminology that was familiar from child services and/or an explanation of new terms. The group also stated that the wording in the leaflets and on the site should be empowering and not patronizing and that the site should be easy to access, colorful and age appropriate. Finally, the AYAs indicated that the information needed to be available in a variety of formats that should include more video 'transition stories' and downloadable information sheets. They also wanted some visual images of the clinics or hospitals that they could be attending; they thought this would help when trying to find the exact location when making their first visit to the new clinic. Further examples of the feedback is listed in Table 4. The suggested changes were incorporated into the website by the web developer and the research team verified that the changes had been successfully made. During the iterative development process, the information materials and website design underwent many changes due to feedback until all groups were in agreement and satisfied with the final product.

Insert Table A.4 here

The website contains nine pages as follows: home page, about transition, clinics and personnel, "top tips", transition stories (nine video testimonials ranging in length from 2.21 to 4.48 minutes), frequently asked questions

(FAQ), essential reading, links and a photo gallery. The video testimonials are also available on YouTube to enhance accessibility. The website contains information on various aspects of the transition process and is presented in several formats. AYAs can watch short videos of 'transition stories', which cover such topics as preparing for transition, the first visit to the adult clinic and talking to the healthcare team. Depending on preferences, users can read or download the transition stories. They can read or download leaflets which provide useful "tips" and information on becoming more independent, knowing about their medications and the differences between child and adult clinics. The site contains a comprehensive question and answer section addressing the key questions identified by our co-designers.

4.2 Phase 4: Launch of website and evaluation

The website was launched in December 2013 by Alan Sothorn, an Irish international hockey player who has T1D. The co-design group and the AYAs who had participated in making the website materials attended the launch with their families. Also in attendance were members of the research team, parents, professionals and representatives from the voluntary organisations who had supported the project. The website has been profiled on numerous websites nationally and internationally, and in the Irish media (Irish Times, and RTE television). It won the Crystal Clear MSD Health Literacy award for best hospital project 2014 in Ireland.

One year after the launch, the *SteppingUP.ie* website was monitored for the number of visitors using Google Analytics. This approach was an attempt to differentiate between initial visitors to the site as a result of the media attention related to the launch and the AYAs for whom the website was designed as an information resource. Starting at the beginning of the year (2015), weekly monitoring of visitor numbers to the site was conducted. Weekly as opposed to monthly checks on visitor numbers allowed for the monitoring of the frequency of visits in relation to any interventions, for example, the introduction of *SteppingUP.ie* awareness programme or related presentations at conferences. In June 2015, the hospitals (n=31) where the AYAs receive chronic illness care were asked to display a poster about the website in the clinic sites to promote awareness of the *SteppingUP.ie* website as a transition resource, amongst service users and professionals. For the first quarter year period 1,055 visitors accessed the site with an average of 81 visitors per week. At the end of the second quarter the cumulative number of visitors to the site was 3,228 with an average of 167 visitors per week. The cumulative number of visitors up to the end of the third quarter was 4,940 with an average of 132 visitors per week. The cumulative number of visits up to the end of the 4th quartile was 6,202 with an average of 97 visits per week for this period. (see Figure A.1 & 2). **To gather opinions and user feedback about the usefulness of the website**, a survey containing ten questions

regarding user satisfaction was developed (by IC & HM) and is now available on the homepage.

Insert Figures A.1 & A. 2 here

4 Discussion and conclusion

4.1 Discussion

For many AYAs the preparation for transition is sub-optimal as they need advice, information, support and signposting in relation to transition but currently encounter obstacles to having these needs met. This co-designed multimedia information intervention is an innovative way of providing relevant information, advice and better preparation for the transition process. The information is presented under three key stages that are: Thinking, Planning, and Making. The *Thinking* Stage is about introducing AYAs to the idea of transition and advising them to start to learn more about their condition and begin to start taking increasing responsibility for their healthcare. For example, under this tab on the website, is a list of “top tips” on how to begin preparing (from other AYAs), information on medications and lifestyle and a list of possible questions that the AYA could ask at their hospital visits. It also provides a link to a short video where a young adult talks about this stage of the transition. It offers AYAs peer support by introducing them to transition stories from their peers. The other stages contain information, “top tips”, possible questions and advice tailored to the stage of transition.

Interventions, such as this one, aim to enhance the AYAs’ knowledge and promote skills in communication, self-care and self-advocacy, which may enhance health status and quality of life [36]. Preparation should begin at an early age and should be an ongoing process, so the website material is worded so that adolescents aged 10 years or older can understand the information. Providing AYAs with timely information and advice on how to prepare for undertaking increasing responsibility for self-management is part of the preparation for transition. AYAs with chronic conditions grow up with the intensive involvement of parents and as a result may never get the opportunity to develop the self-care skills which are essential for a successful transition [37]. Research indicates that adolescents may be relegated to a marginal position in triadic consultations and that healthcare professionals have been slow to engage AYAs in healthcare decision-making [38, 39]. AYAs need information and advice on how to assert their autonomy, become more engaged in clinic consultations and decision-making. This information intervention may empower AYAs to be more actively involved in communication exchanges, which may enhance health-related autonomy and

patient-centered communication [40]. The website provides a list of questions that the AYA could consider asking so that they have the tools with which to begin engaging directly with healthcare providers rather than relying upon their parents to advocate on their behalf.

In developing the website, some challenges were experienced. These included: developing a site and relevant content where none had existed in Ireland, sourcing a web developer (who could undertake both design and coding), videographer and meeting the preferences of all stakeholders. Some of the challenges were overcome through the co-participatory approach and the support and enthusiasm of all those involved. When discrepant opinions arose between the AYAs and adult stakeholders' preferences for design or wording, the AYAs' opinions were always the final decider and the power balance lay with the AYAs. The whole process required flexibility, an open mind, and a willingness to revise material iteratively. We were very fortunate that the co-design group comprised highly committed members who remained engaged throughout the process. It was also very helpful that the web developer was also a film maker and could both design the website and record all the videotapes. He also attended all the co-design group meetings and was present for all feedback and suggestions from the AYAs about the website and materials.

SteppingUP.ie was developed with the AYAs from three long-term conditions (CF, CHD, T1D) but one of the findings from this study was the consistency of views of AYAs on transition information needs. Therefore, the information resources are relevant for AYAs with any long-term condition who will make the transition to adult healthcare, as the key principles are common across disease groups. The website has been expanded to include information and photos of the location and configuration of clinics for epilepsy and cancer adult healthcare. It is a limitation that participants were selected using convenience sampling and thus the sample did not reflect ethnic diversity nor AYAs with disabilities.

4.2 Conclusion

e-health interventions are seen as having the potential to promote empowerment, encourage new relationships between providers and patients, improve efficiency, and enable essential information exchange [41]. However without service-user involvement in the co-design, new interventions can be inappropriate or fail [42]. The participatory co-design approach yielded a reliable, functional, acceptable intervention to support AYAs' needs and requirements for transition to adult healthcare. The intervention is freely available for all AYAs and is the first website on transition that was co-designed by and for AYAs in Ireland. Close collaboration with AYAs ensured that the intervention was developmentally appropriate and resonated with the needs and lives of the AYAs rather than

being professionally dictated. Further research could examine the impact of the website on AYAs' interactions with professionals and also evaluate the merit of delivering tailored interventions to build self-efficacy and self-management skills, for example, smartphones and tablets/iPads[43].

4.3 Practice Implications

SteppingUP.ie is an innovative online resource that can augment gaps when traditional sources of information are less available or non-existent (information from healthcare professionals) or perceived to be less helpful (e.g. written material that is compiled by adults). Providing AYAs with clear information and anticipatory guidance are simple changes in practice that may lead to improvements in transition experiences [10, 21, 44] and a website is particularly relevant for young people with CF who have limited access to peer support due to infection risks. The website is one means of improving information access and preparation for transition, and therefore should be used in conjunction with other initiatives that promote successful transition (e.g. starting the transition process early [44], provision of transition summaries [44], joint pediatric/adult clinics [45], pre-transfer visits to adult clinics and specific young adult clinics[46]. Since transition is a crucial period for AYAs with long-term conditions, it is essential that we develop interventions which enhance their knowledge, encourage engagement with professionals and build on communication and self-care skills, thereby promoting patient-centred care.

Patient details

We confirm all personal identifiers have been removed or disguised so that the persons described are not identifiable and cannot be identified through the details of the story.

Conflict of interest: The authors report no conflicts of interest.

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Figure A.1 Usage of website

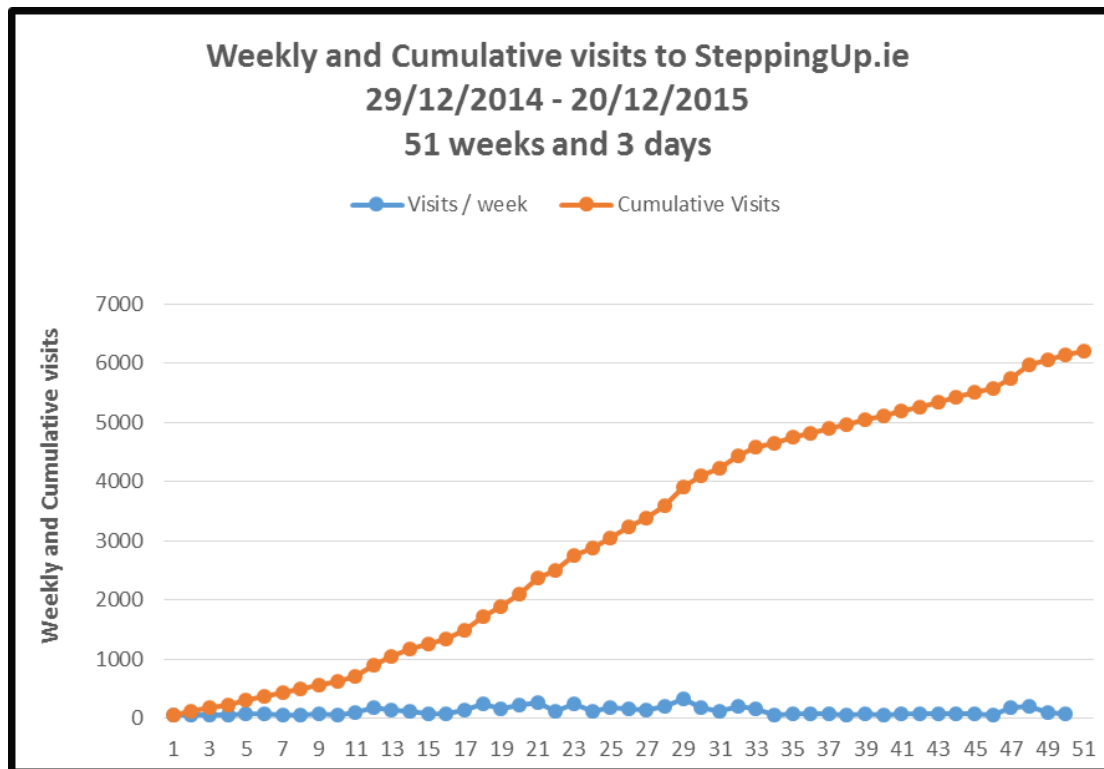


Figure A.2 Viewing numbers for AYAs' video clips on YouTube Nov 2013 - Jan 2016

Adult clinics are different – 424 views
Some advice from young people– 256 views
Preparing for the move - 240 views
Talking to your healthcare team – 208 views
Getting ready for the transition– 204 views
Parents and transition – 108 views
The first visit – 106 views
Getting support is important – 92 views
Gaining more independence– 63 views
Don't let the bad days hold you back – 86 views

Legends

Table A.1 Phases of the research

Phase 1 Consultation and cooperation with relevant stakeholders	<p>Collate AYAs information needs on transition from TRYCIS project.</p> <p>Identify AYAs e-health communication preferences and transition requirements.</p> <p>Establish a co-design group of AYAs with chronic conditions.</p> <p>Establish advisory group of stakeholders from disease & voluntary organizations.</p>
Phase 2 Experimentation	<p>Conduct participatory workshops with AYAs.</p> <p>Develop the information materials.</p> <p>Co-design the website with AYAs.</p> <p>Populating the website with relevant information</p>
Phase 3 Contextualisation and iterative development	<p>Test demos with users & providers.</p> <p>Test out alternative designs.</p> <p>Modification in response to evaluation.</p>
Phase 4 Consultation and cooperation with relevant stakeholders	<p>Launch of website with AYAs and stakeholders.</p> <p>Dissemination of information on website.</p> <p>Evaluation of intervention.</p>

Table A.2: Survey statements and interview questions on eHealth**Survey statements on eHealth**

Please read each statement carefully and place a tick in the most appropriate box.

1. How useful would the following information be during transition?

	Not all	Not at very useful	Moderat ely	Quite useful	Very useful
Personalised results	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Appointments/Reminders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information about the disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Advice/Support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Experience from other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Healthcare facilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. How useful would each of the following ways be to receive or exchange information about the transition?

	Not all	Not at very useful	Moder ately	Quite useful	Very useful
SMS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Twitter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Skype	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Email	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Webpage/website	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chatroom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social Network e.g. Facebook	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. Which way would you prefer to SM Twit Sky Em Webp Chatr Social

receive or exchange each type of S information about transition ?	ter	pe	ail	age Websi te	oom	Netwo rk
Personalised results	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Appointments/Reminders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information about the disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Advice/Support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Experience from other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Healthcare facilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Interview questions on eHealth

Do you own any of the following: (researcher please tick all that apply)

Mobile phone	Smart phone	Blackberry	PC	Laptop	Wizard Kindle	Tablet	Digital TV
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you don't own them, which device do you have access to: (researcher please tick all that apply)

Mobile phone	Smart phone	Blackberry	PC	Laptop	Wizard Kindle	Tablet	Digital TV
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

What do you think about using any or all of these devices to communicate about your health?

What do think about using any or all of these devices to communicate information about the move between child and adult health care services?

What do you think about a dedicated website that contained information and documents about the move to adult services?

What kinds of information would you like to see on it?

How do you think you would like to communicate with healthcare professionals in the future?

Table A.3: Perceived Usefulness of Methods of Receiving Information

Type of Information	Not at all Useful %	Not Very Useful %	Moderately Useful %	Quite Useful %	Very Useful %
Mobile Phone/SMS/apps (n=195)	4.1	5.6	13.4	21.5	55.4
Email (n=193)	8.8	7.3	16.6	26.9	40.4
Webpage/website (n=191)	14.1	9.9	18.9	26.2	30.9
Social Network (e.g. Facebook) (n=193)	21.8	10.4	17.0	22.3	28.5
Chatroom (n=191)	34.0	24.1	16.7	14.7	10.5
Twitter (n=191)	41.9	22.0	18.9	9.9	7.3
Skype (n=191)	42.4	25.7	16.2	13.6	2.1

Table A.4 Selected comments from AYAs about preferences for sourcing information

I think it would be good actually if there was stuff on the internet because people could browse in their own time and also if its not set up on the internet what people could do is just type anything into Google and get the worst information possible about all of the wrong things that they don't need to know that might make them very apprehensive about going whereas I suppose if you had something set up that you could have a look at where you know you are getting definite information about their transition from one hospital to another, that would be good... then if you wanted to ask questions, you could just send an email to someone to ask them or something like that. (AYA with CF)
Like some of the websites I think are very frightening in a way, because you know they nearly give you too much information, eh, they give you worst case scenario rather than, maybe better case scenario (AYA with CHD)
It would great to have a website that was recommended by the children's hospital, you know, something that had just enough information (on transition), and safe sensible information to give you, you know, until you found your feet in the adult hospital because em, we found it all quite, quite traumatic (AYA with CHD)
I love Twitter and stuff like that, on the moment as it happens, kinda just lots of information and been able to communicate really easily and really quickly and know just, know different things like but if I was going to read anything, I'd read it off the Internet, I wouldn't sit down and read a book or anything like that (AYA with CHD)
I looked up some stuff, but then I don't really know what I was looking for and then it like I think I'm reading the wrong thing here and then I'm like I think oh god I didn't want to read something that was wrong (AYA with CHD)
It would be good if there was probably a website for young people about diabetes or other illnesses or something like that and then if they were to transfer from a child's clinic to an adult, just to know like if they put up their opinions on it just to read them or something that would probably be good. So then you'd know what you are getting into and you know what it's like. So it's just more information on top of the information that the hospital could give you about it which would be really handy (AYA with diabetes)
I would like to hear from younger people like my age so if I'm moving in like my age person has already moved into the adult clinic to tell me you know what's it like, what's it about, their opinion on going in, transferring in which would be good (AYA with diabetes)

Table A. 5 Selected comments on website development from AYAs and adult stakeholders

<p><i>Comments on the wording</i></p> <p>The 'branding' for the leaflets should be the same as that used in the 'transition story' video – a single 'trainer' footprint with the word 'SteppingUP.ie' imprinted over it.</p> <p>Where possible, the word 'condition' as opposed to 'illness' should be used on the site and materials. It was suggested that the term 'illness' sounds too depressing.</p> <p>In the leaflet about 'achieving independence', the phrase 'gain independence' should be replaced with 'achieve more independence'.</p> <p>In the 'Top Tips' for 'thinking about transition (12-14 years)' the tip about knowing who to contact in an emergency should be removed. It was felt that parents were more likely to be the first to be contacted by this age group in an emergency. This tip was placed in the 'making the transition (age 18 years onwards)' top tip page.</p> <p>In the leaflet about talking to the healthcare team it was felt that it would be very important for young people to know that they did not have to remain silent if they were experiencing difficulties at any stage during the transition process. A 'tip' about 'not suffering in silence' was added at this stage.</p>
<p><i>Comments on the navigation and usability</i></p> <p>The support and guidance that <i>SteppingUP.ie</i> is offering is exactly what young people with diabetes need at this time in their lives. With so many changes happening around this age, the worry of transitioning from childcare to adult services in as seamless a manner as possible is something that shouldn't impact those affected, which prior to this website it may have (Young adult).</p>
<p><i>Comments on the usefulness of the intervention</i></p> <p>Well done, this is an excellent example of money being put to good use. My daughter lives well with a congenital heart issue and goes to her first adult appointment this Friday so the timing couldn't be better (Parent)</p> <p>For young people, with long-term conditions, the period of transition from paediatric to adult services can be very difficult. This new website will help young people to understand the process of transition and prepare for a safe and successful transfer of care to adult services (Consultant Endocrinologist).</p>
<p><i>Comments on participating in the co-design group</i></p> <p>I was grateful to be included as it felt fulfilling to give something back. Putting my own illness experiences into a context that would assist others with the same illness felt really rewarding. I jumped at the opportunity to help with the project and enjoyed every aspect of it (Young adult).</p>